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DOI:

[10.1016/j.pec.2013.10.008](https://doi.org/10.1016/j.pec.2013.10.008)

Document Version

Early version, also known as pre-print

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Citation for published version (APA):

Brohan, E., Henderson, C., Slade, M., & Thornicroft, G. (2014). Development and preliminary evaluation of a decision aid for disclosure of mental illness to employers. *Patient Education and Counseling*, 94(2), 238-242. <https://doi.org/10.1016/j.pec.2013.10.008>

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Citation: Brohan E, Henderson C, Slade M, Thornicroft G (2014) *Development and preliminary evaluation of a decision aid for disclosure of mental illness to employers*, Patient Education and Counseling, **94**, 238-242.

Development and preliminary evaluation of a decision aid for disclosure of mental illness to employers

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Abstract

Background: Many mental health service users delay disclosing to employers or never do so due to previous experience of, or anticipation of discrimination. However, non-disclosure precludes requesting 'reasonable workplace adjustments'. Service users may experience conflicting needs and values in deciding whether to disclose. No evidence-based interventions exist to support this decision.

Method: A decision aid (CORAL, or CONceal or ReveAL) to support mental health service users in reaching disclosure decisions was developed and subjected to preliminary evaluation (n=15).

Results: The majority found the decision aid quick (60%) and relevant (60%) and would recommend it (80%). Eighty percent reported that they would definitely or probably use it in making disclosure decisions. Forty percent each were positive or neutral on its ease of use. Semi-structured interviews revealed a demand for more information on the legal implications of disclosure. The mean level of 'decisional conflict' regarding disclosure reduced from 52.0 to 35.5 and mean Stage of Decision-making Scale score from 4.6 to 4.3.

Conclusions: The results suggest that the CORAL decision aid is feasible, relevant and valuable in supporting decisions about disclosing a mental illness to an employer.

Practice Implications

The decision aid could be deployed in routine care without significant resource implications.

Keywords: decision support techniques; disclosure; employment; mental health

1. Introduction

The decision of whether to disclose a mental health problem to an employer is very difficult for many mental health service users [1]. On one hand, disclosure is a pre-requisite for requesting workplace 'reasonable accommodations' (or 'reasonable adjustments'). For example, over three quarters of UK employers believe that people with mental health problems should disclose their problem prior to employment[2;3], although pre-employment health questions have been made unlawful except in certain circumstances by the UK Equality Act 2010[4]. On the other, many people with mental health problems experience discrimination, either when seeking work or in employment, and many either conceal their problem from employers or avoid seeking work due to the anticipation of discrimination[5-7]. These problems contribute to low employment rates for people with mental health problems[8;9].

A recent systematic review highlighted the role of stigma and discrimination as a barrier to finding and keeping work for individuals with a mental health problem[10]. Applicants with a mental health problem

are commonly rated as less employable than either a candidate with a physical disability (e.g. diabetes, back injury) or a candidate with no disability [11-18]. Four assumptions have been proposed as underlying stigmatising employer attitudes towards individuals with mental health problems in the workplace: 1) people with mental health problems lack the competence to meet the demands of work; 2) people with mental health problems are dangerous or unpredictable in the workplace; 3) working is not healthy for people with mental health problems; and 4) providing employment for people with mental health problems is an act of charity and not something that non voluntary sector employers need to engage in [19]. These persisting beliefs, and the consequent reduced likelihood of being hired, highlight the difficulty inherent in deciding what, if anything, to tell a potential employer about a mental health problem.

This paper describes the development and pilot testing of a decision aid to assist people with mental health problems in reaching decisions regarding disclosure in the employment context. A decision aid is an educational intervention designed to help an individual make a specific and deliberate choice between two or more options. They are commonly used in medical decision-making when individuals need to choose between treatment or screening options [20]. A systematic review of 17 randomised trials of decision aids found that, compared with controls, decision aids produced higher knowledge, more active participation in decision making and lower levels of decisional conflict [21]. This suggests that a decision aid may be a useful intervention to increase knowledge about disclosure, reduce decisional conflict, and increase active participation in making a disclosure decision.

Our aims were to: (1) develop a decision aid for making decisions regarding disclosure of a mental health problem in employment settings; (2) evaluate it for preliminary evidence of feasibility, acceptability and effectiveness.

2. Methods

This was a mixed-methods pilot study using convenience sampling.

The study received National Research Ethics Service (NRES) approval from the Joint South London and Maudsley and Institute of Psychiatry research ethics committee (REC ref: 07/Q0706/21).

Measures

Participants completed three measures. The Stage of Decision Making Scale measures the individual's readiness to engage in decision making [22]. It consists of 1 item with 6 response options anchored at 1=haven't started to think about the choices and 6=have already made a decision and am unlikely to change my mind).

The Decisional Conflict Scale measures personal perceptions of: uncertainty in choosing between options; modifiable factors contributing to uncertainty including feeling uninformed, lack of clarity about personal values and feeling unsupported in decision making; and effective decision making such as feeling the choice is informed, values-based, likely to be implemented and expressing satisfaction with

the choice. The 16 item version of the scale is the most commonly used [23]. Each item is rated on a five- point Likert scale ranging from 0=strongly disagree to 4=strongly agree. A total score and five subscores (uncertainty; informed sub-score; values clarity sub-score; support sub-score and effective decision sub-score) are generated. Scores are generated by summing the items, dividing by the number of items in the subscale and multiplying by 25. Scores range from 0=no decisional conflict to 100=extremely high decisional conflict. The scale has demonstrated adequate test-retest reliability [24] and has also acceptable internal consistency when used with people with a diagnosis of schizophrenia [25]. Scores exceeding 37.5 are associated with decisional delay or feeling unsure about implementation.

Participants were also asked to complete four items measuring the quickness, easiness and relevance of the decision aid and whether they would recommend the decision aid to other people who wanted to make disclosure decisions. All items were rated on a five point Likert scale.

Sample

Included participants were aged 18 years or older; had used specialist mental health services on one occasion or more in the past 12 months; were currently seeking either paid or voluntary employment; had a Decisional Conflict Scale score of 37.5 or greater indicating a moderate level of decisional conflict, and a Stage of Decision-making Scale score of 1-5, indicating they had not already made a decision about which they were unlikely to change their mind. Participants were excluded if they were unable to speak English sufficiently well to take part in the interview; unable to read English sufficiently well to complete

the decision aid; or lacked capacity to consent (e.g. due to active mental illness). Participants were recruited from a community mental health team via members of the clinical team.

Intervention

The disclosure decision aid was developed using the Ottawa decision support framework [26], drawing on the results of the systematic review and on qualitative interviews [27] with mental health service users about disclosure in a variety of employment contexts. The Ottawa decision support framework is a guide for the development and evaluation of patient decision aids to promote shared decision making in health care [28]. As disclosure in the employment context may or may not be a shared decision e.g. with a mental health professional or vocational adviser, the framework was adapted by incorporating elements from the Theory of Planned Behaviour [29]. This theory has been used in considering both medical and non medical decisions [30-34]. It suggests that human actions are influenced by three main factors: 1) a favourable or unfavourable evaluation of the consequences of the behaviour (i.e. attitude); 2) perceived social pressure to perform or not perform the behaviour (i.e. subjective norm); and 3) perceived control over performance of the behaviour (i.e. perceived behavioural control). These factors are linked to a corresponding set of behaviour-related beliefs which work in combination to produce behavioural intent.

It is clear from the application of this theory that the decision aid must help its user consider not only all the possible consequences of both disclosure and nondisclosure, but of when to disclose and to whom. Attitudes towards disclosure are determined by beliefs about the likelihood of these consequences, which can be assessed using measures of experienced [35], anticipated [36] self- [37] and perceived stigma [38]. Second, the subjective norm is influenced by the person's normative beliefs which in this context concern e.g. those regarding honesty, privacy, and the individual's right to decide. The decision

aid should therefore help users to consider these norms and weigh up their own beliefs about them. The last contributor to the behavioural intent i.e. to disclose or not is the degree to which the person feels that disclosure is under their control. Users of the decision aid therefore need to consider whether involuntary disclosure is a risk, for example through currently observable symptoms or side effects of medication, or through future relapse of illness. Further, the need to disclose in order to retain employment through access to reasonable workplace adjustments reduces control over disclosure unless the person wishes to tolerate an increased risk of not being able to perform the job. We propose that levels of self-esteem, empowerment, and coping orientation may influence control beliefs and behaviours and therefore disclosure decisions. Last, the themes identified from the systematic review and qualitative interviews[10;27] of trust, taking care, proving oneself first and the role of the employer suggest that the relationship between the individual and the target of their disclosure are also important.

Feedback on the draft decision aid was obtained from colleagues including a vocational rehabilitation team manager, a service user researcher, two psychiatrists, and a psychologist.

Potential participants were identified by the care-coordinator or other relevant clinical personnel using the inclusion and exclusion criteria as above. The researcher (EB) scored the eligibility questionnaires and telephoned potential participants to inform them whether they were eligible and provide study information to those who were. The interviews were conducted at the mental health service premises. Before the interview, participants were given the participant information to read and asked if they had any questions. After this written informed consent including permission to access case notes to record current diagnosis was obtained. Interviews lasted a maximum of 1.5 hours.

Procedures

All participants were first asked to complete the Stage of Decision-making Scale and the Decisional Conflict Scale. They were then presented with the decision aid and asked to read and complete it. This process was conducted with minimal involvement from the researcher. The researcher's main role was to record the time taken to complete the decision aid and to record any questions or areas of confusion which arose. If the participant had difficulty in understanding the decision aid then it was explained that part of the purpose of the study its ease of completion and they should use their best guess to answer questions. If this was not sufficient then a more complete description was provided, with the researcher guiding the participant through the decision aid as an interview if necessary. After completion of the decision aid participants rated the decision aid for brevity, simplicity and relevance, using an established framework to assess the feasibility of routine outcome measures [39]. They also repeated the Stage of Decision-making Scale and the Decisional Conflict Scale and a brief demographic and clinical questionnaire.

An audio-recorded semi-structured interview was then administered to obtain further feedback on the decision aid. We asked participants their general opinions on the decision aid; other information/experiences which should be included in it; amendments to existing information; and - whether participants would use it to make disclosure decisions and recommend it for others in a similar situation.

Analysis

Analysis was performed using SPSS version 15 [40]. Descriptive statistics for the socio-demographic and decision aid rating variables were calculated. The significance of the changes in scores on the Decisional Conflict Scale and Stage of Decision-making Scale were not assessed, as the study was designed to give an estimate of effect size rather than powered to detect a significant change. Further analysis focused on assessing the acceptability and feasibility of the decision aid. Analysis of interview transcripts was conducted using NVivo software [41]. The methods of content analysis were used to present count and verbatim examples of the main themes encountered during the open ended questions [42].

3. Results

The decision aid comprised six sections: (1) 'Pros and cons' of disclosure. (2) My disclosure needs (3) My disclosure values. (4) When to tell. (5) Who to tell (selectively or wider disclosure) (6) Making a decision (summarises the previous sections and asks the participant to reflect on responses and make a decision regarding whether and if so when, what and to whom to disclose). To maximise the accessibility of language in the decision aid relevant verbatim quotes from qualitative transcripts [27] were included in sections 2-5. The revised version received a Flesch Reading Ease score of 65.6 and a revised Flesch-Kincaid Grade level of 8.4 i.e. understandable by the average US 8-9th grader aged 13-15 years.

15 people took part in the study. 53% were male, and the majority identified as white British (53%). Most participants were currently in voluntary employment (47%) or unemployment (40%). The most common self-reported diagnosis was bipolar disorder (47%). Further characteristics are presented in Table 1.

Table 1 about here

The mean time taken to complete the decision aid was 29 minutes (SD 8.8), with time taken ranging from 11 minutes to 45 minutes. The Decisional Conflict Scale score and sub-scores and Stage of Decision-making Scale scores are presented in Tables 2 and 3 respectively. Mean Decisional Conflict Scale scores reduced from 51.98 to 35.52 after completing the decision aid while the mean Stage of Decision-making Scale score reduced from 4.6 to 4.3.

Tables 2 and 3 about here

Responses to the additional questions on the decision aid are presented in Table 4. These suggest that the majority of participants found the decision aid quick (60%), relevant (60%) and would recommend it to others (80%). 80% reported that they would definitely or probably use the decision aid in making disclosure decisions. An equal number of participants were neutral and positive on the easiness of the decision aid (both 40%) suggesting that this is an area that could be improved. Semi-structured interviews revealed a demand for more information on the legal implications of disclosure.

Table 4 about here

4. Discussion and Conclusions

4.1. Summary of results

The finalised decision aid demonstrated initial acceptability and feasibility in a group of 15 service users. Mean Decisional Conflict and Stage of Decision-making Scale scores reduced after completing the decision aid. While the majority reported that it was quick to complete, relevant, and that they would use it and recommend it to others, fewer found it easy to complete. In support of this quantitative finding is that from the content analysis, where the highest number of negative sub-themes was found in theme 'simple'. This suggests that further simplification may be needed. However, over-simplification could reduce the effectiveness of this tool; the emphasis on needs, values and experiences highlighted in the codes suggests that the decision aid was successful in getting participants to think through core elements related to disclosure decisions, and these elements reflect the complexity of the disclosure decision.

The qualitative work highlighted areas in which further improvements could be made. One area of need identified is that for a better understanding the legal situation regarding disclosure. To this end we are now working with colleagues in computer science and law on an additional decision support tool, namely a computer system applying the Equality Act 2010 to mental health problems[43]. Based on the Act, accompanying guidance, and relevant employment legislation, it can inform a lay person using his/her responses to questions, whether (a) s/he has a disability according to the Act, (b) his/her employer may be required to provide reasonable adjustments, and (c) the employer may have discriminated against them on grounds of disability. This work could be replicated for equalities legislation for other jurisdictions.

4.2. Strengths and limitations

The theoretical perspectives provided by the Ottawa decision support framework [26] and Theory of Planned Behaviour [44], and an integrated disclosure framework developed from qualitative work[27] and the systematic review[10], were used as the theoretical basis for this decision aid. Alternative theoretical perspectives to the Theory of Planned Behaviour have been used in similar work, for example social cognitive theory has been used in developing a model of disclosure of HIV sero-positivity to sexual partners [45]. However, it was felt that the Theory of Planned Behaviour was most appropriate in understanding disclosure beliefs and behaviours in the employment context. The theoretical focus on behavioural beliefs is supported by the super-ordinate theme of 'personal impact of labelling', the subjective norm is reflected in the super-ordinate theme of 'public understanding of mental illness', while control beliefs are represented in the subtheme 'control of information' which is part of the super-ordinate theme 'disclosure needs'.

This study was strengthened by screening participants so that an appropriate sample was selected. To participate, individuals needed to indicate at least a moderate level of decisional conflict (as assessed using the decisional conflict scale) and also select a stage of decision making which indicated that they had not already made a firm decision which was unlikely to change (as assessed using the stage of decision making). This process ensured that the decision aid was being applied in a sample of people, for which a clarification of disclosure needs and values were desirable. This study is further strengthened by the use of a mixed methods approach which allows the change in scores to be interpreted in terms of the qualitative data. A limitation is that the sample size was not powered to detect statistically significant change in scores on either the decisional conflict or the Stage of Decision-making scale.

Within the sample only two were in open employment; this small proportion together with the small

sample size means it is not possible to discern the potential effectiveness of the decision aid for people already in work. Further, no follow up was conducted to assess whether any pre post change in the scores persisted over time. Last, the sample was drawn from secondary mental health services and thus the results may not be generalizable to other populations who also have to decide whether to disclosure to employers, such as those seen for mental health problems within primary care.

4.3. Implications for research

Ultimately we wish to determine through a randomised controlled trial whether using the decision aid changes the user's behaviour with respect to seeking or retaining employment in ways that result in higher levels of employment and greater use of workplace accommodations. To determine whether such a trial is justifiable and feasible, and to optimize its design, our next step is to conduct a proof of concept RCT[46]. To investigate the implications for practice such a trial should include vocational advisers' views on incorporating the decision aid into their practice.

Declaration of interests

The authors declare that they have no competing interests.

Acknowledgments

This research was supported by funding from the Trustees of South London and Maudsley NHS Foundation Trust. Support was also provided by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research scheme (RP-PG-0606-1053). The views expressed in this

publication are those of the author(s) and not necessarily those of the Trustees of SLAM, the NHS, the NIHR or the Department of Health. GT and MS are also funded through a NIHR Specialist Mental Health Biomedical Research Centre at the Institute of Psychiatry, King's College London and the South London and Maudsley NHS Foundation Trust.

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Table 1. Demographic characteristics of interview participants (n=15)

Variable		N	%
Gender	Male	7	46.7
	Female	8	53.3
Ethnicity	White British	8	53.3
	Black African	3	20.0
	Black Caribbean	1	6.7
	Black British	1	6.7
	Other white background	1	6.7
Highest level of education	Secondary school	6	40.0
	Higher diploma or degree	5	33.3
	Vocational qualification	3	20.0
	Postgraduate degree	1	6.7
Employment status	Employed	2	13.3
	Volunteer	7	46.7
	Unemployed	6	40
Diagnosis	Bipolar disorder	7	46.7
	Depression	3	20
	Depression and anxiety	1	6.7
	Don't know	2	13.4
	Personality disorder	1	6.7
	Schizophrenia	1	6.7
Age	Mean (SD)	41.5 (6.5)	

Table 2. Decisional conflict scores

Variable	Pre-completion		Post-completion		Difference	
	Mean	SD	Mean	SD	Mean	SD
Total decisional conflict (Range 0-100)	52.0	14.0	35.5	13.9	16.5	17.5
Uncertainty (Range 0-100)	63.9	23.3	43.9	23.7	20.0	20.9
Informed (Range 0-100)	53.3	23.5	35.6	22.6	17.8	19.4
Values clarity (Range 0-100)	48.9	24.2	31.7	19.0	17.2	25.1
Support (Range 0-100)	55.0	20.6	40.6	20.4	14.4	19.0
Effective decision (Range 0-100)	42.8	21.1	28.9	18.1	13.9	21.8

Table 3. Stage of decision making scores

Response	Pre-completion		Post-completion	
	n	%	n	%
Haven't begun thinking about the choices but am interested in doing so	1	6.7	0	0
Are considering the options now	3	20	2	13.3
Are close to selecting an option	2	13.3	5	33.3
Have already made a decision but am willing to reconsider	9	60	5	33.3
Have already made a decision and am unlikely to change my mind	0	0	3	20
Mean score (SD)	4.3	1.0	4.6	1.0

Table 4 Responses to additional decision aid questions

Variable	Very positive		Quite positive		Neutral		Quite negative		Very negative		Mean	SD
	n	%	N	%	n	%	n	%	n	%		
How quick was it to complete the decision aid?	1	6.7	8	53.3	1	6.7	5	33.3	0		2.67	1.05
How easy was it for you to complete?	1	6.7	5	33.3	6	40	3	20.	0		2.73	.88
How relevant was the decision aid for you?	6	40	3	20	4	26.7	2	13.3	0		2.13	1.13
Would you recommend the decision aid to other people?	6	40	6	40	3	20	0		0		1.80	.77

